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Title: A national survey exploring views and experience of health professionals about transferring patients from critical care home to die

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What is already known about the topic?

- Transferring patients home at end of life is an important part of health policy but poorly explored in critical care settings.

What this paper adds?

- This study demonstrates that 51.6% of UK senior nurses and medical consultants in this survey had experience of either transferring a patient home to die or of being involved in such discussions.
- This is the first study to identify characteristics of patients (unstable, ventilated via an endotracheal tube, receiving inotropic support) who are not considered suitable for transfer home to die, from the perspective of senior nursing and medical staff in critical care.

Implications for practice, theory or policy?

- Results demonstrate transfer home to die is occurring in critical care areas.
- More clinical guidance would assist in decision making to identify appropriate patients for this practice.

Abstract

Background: Transferring critically ill patients home to die is poorly explored in the literature to date. This practice is rare and there is a need to understand health care professionals (HCP) experience and views.

Objectives: To examine 1) HCPs experience of transferring patients home to die from critical care, 2) HCPs views about transfer, and 3) characteristics of patients HCPs would hypothetically consider transferring home to die.

Design: A national study developing a web-based survey, which was sent to the lead doctor and nurse in critical care units.

Setting/participants: Lead doctors and senior nurses (756 individuals) working in 409 critical care units across the UK were invited to participate in the survey.

Results: 180 (23.8%) completed surveys were received. 65 (36.1%) respondents had been actively involved in transferring patients home to die and 28 (15.5%) had been involved in discussions that did not lead to transfer. Respondents were supportive of the idea of transfer home to die (88.8%). Patients identified by respondents as unsuitable for transfer included: unstable patients (61.8%), intubated and ventilated patients (68.5%) and patients receiving inotropes (65.7%). There were statistically significant differences in views between those with and without experience, and between doctors and nurses. Nurses and those with experience tended to have more positive views.

Conclusions: Whilst transferring patients home to die is supported in critical care, its frequency in practice, remains low. Patient stability and level of intervention are important factors in decision making in this area. Views held about this practice are influenced by previous experience, and the professional role held.

Keywords: preferred place of death, choice, transfer, intensive care

Introduction

With increasing interest in provision of high quality critical care at end of life, best practice examples are now available that focus on enhanced decision making processes,¹ communication interventions² and improved collaborative working.³ However, place of death for a critically ill person is often not explored. With international health policy supporting increased choice for patients at end of life,^{4,5} the question arises as to what extent this choice is reinforced in practice in critical care units, rather than the place of treatment withdrawal dictating the place of death.

To a great extent end of life care is influenced by the clinical characteristics of patients in critical care. Critically ill patients tend to be clinically very unstable and time between withdrawal of treatment and death is likely to be short. This leaves clinicians and families with very little time to make important decisions and organise a transfer home if this is the desired course of action. Transfer home to die from critical care in order to facilitate the choice to die at home is relatively rare in this population.⁶⁻⁸

There are several studies describing attempts to honour preferred place of death in critical care, by transferring patients home to die.⁶⁻¹⁶ These publications describe the complexity of this practice, as well as the importance of cultural influence. Health services in several countries, such as Taiwan and New Zealand, have responded to the desire to enable patients to die at home, by providing the option of transferring patients home at the end of life from critical care.⁶⁻⁸ However, these countries are in the minority regarding this practice, most probably due to perceptions about the multiple and complex obstacles that would need to be overcome when attempting to

transfer a patient who is receiving very high levels of complex care, possibly including mechanical ventilation, and/or cardiovascular support. However, as it is possible to transfer patients from critical care to other secondary or tertiary care settings and this is done with some regularity the question arises as to why patients are not more routinely being transferred home to die. While views of doctors and nurses on treatment withdrawal and end of life care have been well explored in the literature,^{17,18} there is no evidence to date on the views held by health care practitioners (HCP) on the practice of transferring critically ill patients home to die. Published work has described the overwhelmingly positive views of this practice of those health professionals who have facilitated such a transfer.⁹⁻¹³ However, these data are limited to case reports and editorials, and thus unlikely to be representative of the views of critical care health professionals more generally, including those who have never been involved in such a transfer.

Another aspect that is largely unknown is the number of health professionals who have experience of transfer home to die. Whilst there is international data on mortality rates of patients who die in critical care,¹⁹⁻²¹ these data do not include an indication of the number who died at home. A study from Taiwan⁷ reported between 24%-44% of patients having been transferred home during a 5 year period, while a study from New Zealand⁸ reported a total of 17 patients being transferred in 6 years. It is likely that these numbers are influenced by the cultural context of the country and therefore we were interested to explore health professionals experience in a country where this practice is less well-established.

The characteristics of patients who die in intensive care have been well described,^{22, 23} but data on the types of patients, or detail on the characteristics of patients that may indicate that transfer home could be feasible, is lacking. Published studies have focused on the issue of mechanical ventilation,^{9,14} with one study reporting transfer of such a patient home to die,¹⁴ whereas another study emphasise that this would likely prohibit transfer home to die.⁹ This links to the issue of withdrawal of treatment at the end of life, and the views of health professionals as to whether this would be feasible to achieve in the home, rather than in hospital. Therefore the current study sought to explore health professionals' views about potentially transferring a patient home to die, taking into account specific patient characteristics (e.g. on mechanical ventilation, receiving high level inotropes).

The study also sought to investigate whether those with experience of transfer report more positive views about feasibility and appropriateness of transfer compared to those without experience of this practice.

Design

A large three phase mixed methods study was undertaken to investigate transferring patients in critical care home to die. In Phase I a literature review was carried out and focus groups were held with community, critical care health professionals and user stakeholders. In this phase the web-based survey was also developed and sent to intensive care health professionals. Follow-up telephone interviews were held with participants with experience of taking patients home to die. In Phase II the size and characteristics of the critical care patient population was established through a

retrospective (12 month) case note review from five adult critical care units. In Phase III a national workshop was held for key stakeholders to identify key service characteristics necessary to achieve effective transfer. This paper reports on results from the national web-based survey of health care practitioners where the objectives were to: examine 1) HCPs experience of transferring patients home to die from critical care, 2) HCPs views about transfer, and 3) characteristics of patients HCPs would hypothetically consider transferring home to die

Methods

Findings from a previous scoping review and focus groups (reported elsewhere) were synthesised to inform development of a web-based survey. The survey was designed to explore experience and views towards transferring patients in critical care areas home to die from the perspective of lead nurses and medical consultants of critical care units in the UK.

Survey development

The survey drew on three main categories developed from earlier focus group findings: experience, views, and patient characteristics (see Figure 1).

Figure 1 in here.

Section 1 of the survey collected demographic information about the respondent and their unit. Section 2 explored prior experience with transfer home to die or discussions held about possible transfers. Section 3 contained 17 statements on views about

transfer home to die. Respondents were asked to indicate to what extent they agreed or disagreed with the statements on a five-point Likert scale (1=strongly disagree to 5=strongly agree). Section 4 contained a list of patient characteristics and respondents were asked to indicate whether they would consider transferring a patient with these characteristics home to die. Respondents were asked to make a forced choice between 'yes' and 'no'. The survey was pilot-tested with 23 doctor and nurse volunteers, from 3 intensive care units, and seven experienced researchers from the Faculty of Health Sciences at the University of Southampton (UK). This process allowed content validity and face validity to be assessed.

The survey was administered online using ISurvey software, a package developed by the Department of Psychology at the University of Southampton (UK).

Sample and Recruitment

A list of all critical care units (excluding Paediatric Intensive Care Units and Neonatal Intensive Care Units) in England, Scotland, Wales and Northern Ireland, including phone and email contact details of the lead medical consultant and lead nurse was compiled by the research team. The UK Intensive Care Society previously published a compilation of all intensive care units in the UK. However the contact details for the lead doctor and nurse were outdated and therefore each unit was telephoned to obtain updated contact details. The web-based survey was sent out (June/July 2012) to all lead consultants and lead nurses on this list of units (n=409). Two reminders were sent after ten and twenty days. In total 756 health care professionals received an invitation to participate in the web-based survey (n=62 health professionals did not receive an invitation due to incorrect contact information).

Data analysis

Frequencies were expressed in raw scores and percentages with responses to the 'views' statements also presented as medians (range). Further subgroup analyses using non-parametric tests (Mann-Whitney U test) were carried out using Predictive Analytics SoftWare (PASW) 19.0²⁴.

Results

Respondent characteristics

A total of 191 health care practitioners completed the questionnaire (or sections of it) and 180 respondents provided sufficient data for analysis (11 health care practitioners only completed the questions on demographic information and did not complete any questions after this first section). This represents a response rate of 23.8%. Of the 180 respondents, 71 were senior doctors and 97 senior nurses (n=12 participants did not provide sufficiently clear information to ascertain whether they were a nurse or a doctor).

The majority of respondents indicated that the speciality of their unit was general intensive care (n=117, 65%). 11% (n=19) indicated working on coronary care/cardiology, and the remainder of respondents indicated the following as the speciality of their unit: neurology (n=11), cardiac surgery (n=8), medical (n=6), surgical (n=1), oncology (n=1), burns (n=1), liver (n=1), trauma (n=1), respiratory (n=1), or combinations/mixed units (data were missing for 4 respondents). The number of beds for each unit ranged from 3 to 80, median = 12.

Transfer critically ill patients home to die: Experience

65 (36%) participants indicated they had experience of transfer home to die in the last three years. Of those with experience 20 (31%) had transferred 1 patient home to die, 15 (23%) had transferred 2 patients, 12 (19%) had transferred 3 patients, 1 (2%) had transferred 4 patients, 1 (2%) transferred 5 patients and a further 6 (9%) had transferred more than 5 patients home to die (data were missing for 10 participants). Investigating differences between doctors and nurses did not find a difference between these two groups in terms of experience (32.4% of doctors versus 38.1% of nurses had experience of transfer home, $p=0.44$)

28 (16%) did not have experience of a transfer home to die but had held discussions about transfer home to die. In terms of the numbers of patients that discussions were held about, 6 (21%) respondents had discussions about 1 patient, 14 (50%) about 2 patients, 4 (14%) about 3 patients and one respondent (4%) had had discussions about more than 5 patients. Data was missing for 3 respondents. In the sample 87 (48%) respondents did not have any experience of transfer home to die, nor had any discussions about transfer home to die.

Transfer critically ill patients home to die: Views

The results from the respondents' views on transfer home to die (Table 1) indicated that respondents held positive views about transfer as illustrated by 'transferring critically ill patients home to die is important because patients should be able to die at home if that is their preferred place of death' (strongly agree=33.1%, agree=49.1%). Respondents tended to disagree with statements such as 'taking critical care patients

home to die is a waste of health care resources' (strongly disagree =32.4%, disagree =51.8%) or 'critical care staff have more pressing clinical priorities than organising home transfers for dying patients' (strongly disagree=19.9%, disagree=53.0%).

Table 1 in here

Subgroup analyses

Respondents with experience of transfer were more likely to agree with statements about being able to achieve transfer, such as 'we would be able to organise the transfer home to enable someone to die at home' (strongly agree or agree 79.7% versus 48.1%, $p=0.000$), 'patients will still receive the best possible care if they are transferred home to die' (strongly agree or agree 65.1% versus 41%, $p=0.003$), as well as emphasising its importance in light of choice, 'transferring critically ill patients home to die is important because patients should be able to die at home if that is their preferred place of death' (strongly agree or agree 87.3% versus 79%, $p=0.028$). The respondents without experience of transfer were more likely to agree with statements about lack of experience ('I have limited experience of transferring patients home to die and wouldn't know where to start' (strongly agree or agree 50.4% versus 9.4%, $p=0.000$), concerns (e.g. 'it would be too distressing for the patient and relatives to take them out of the familiar critical care environment' (strongly agree or agree 6.5% versus 6.3%, $p=0.011$). In addition, those without experience were more likely to agree that ITU as a good place to die (e.g. 'it is more important to offer good end-of-life care on the unit than to transfer patients home to die' (strongly agree or agree 3.7% versus 3.1%,

$p=0.014$, or that 'taking critical care patients home to die is a waste of health care resources' ((strongly agree or agree 7.5% versus 0.9%, $p=0.000$).

Differences between doctors and nurses were found for several questions. Nurses were more likely to agree with statements than doctors indicating more positive views on the items: 'It is satisfying to enable a patient to die at home' (strongly agree or agree 86.7% versus 81.4%, $p=0.018$); 'patients will still receive the best possible care if they are transferred home to die' (strongly agree or agree 56.7% versus 4.03% , $p=0.035$); 'transferring critically ill patients home to die is important because patients should be able to die at home if that is their preferred place of death' (strongly agree or agree 89.9% versus 72.4%, $p=0.000$) and 'transferring critically ill patients home to die is a feasible option in critical care (strongly agree or agree 73.9% versus 52.1%, $p=0.001$). Nurses were more likely than doctors to disagree with the statements; 'critical care staff have more pressing clinical priorities than organising home transfers for dying patients' (strongly disagree or disagree 86.2% versus 55.8%, $p=0.002$) and 'taking critical care patients home to die is a waste of health care resources' (strongly disagree or disagree 88.9% versus 78.3%, $p=0.002$).

Transfer critically ill patients home to die: Patient characteristics

Participants were asked to indicate whether they would consider transferring a patient home with a specific characteristic. Table 2 outlines the responses with 'yes' or 'no' being the only response options. The majority of participants responded 'yes' to most characteristics except for patients described as either: unstable (yes $n=63$ (38.2%), no $n=102$ (61.8%), ventilated via an endotracheal tube (yes $n=52$ (31.5%), no $n=113$

(68.5%), or needing cardiovascular support (e.g. inotropes; yes n=57 (34.3%), no n=109 (65.7%). Participants were divided regarding patients who were ventilated via tracheostomy (yes n=96 (57.8%), no n=70 (42.2%).

Table 2 in here

Subgroup analyses

Differences between doctors and nurses were found in terms of potential consideration for transfer based on patient characteristics. Nurses were more likely to record 'yes' than doctors to transferring a patient home who is 'unconscious' (69.4% versus 53.7%, $p=0.047$), 'has intense nursing needs e.g. frequent turning and washing' (88.4% versus 61.2%; $p<0.000$) and 'has relatives with high level emotional needs' (86.0% versus 67.6%, $p=0.006$). On the other hand doctors were more likely to record 'yes' than nurses to transferring a patient home who 'needs cardiovascular support e.g. inotropes' (45.6% versus 26.7%, $p=0.015$).

Discussion

The study investigated in a large sample health professionals' experience and views of transfer of critically ill patients home to die, as well as the associated characteristics of patients. Whilst this practice has been previously reported to be an uncommon event in critical care,⁶⁻¹⁶ in excess of a third of respondents to this survey had been involved in transferring between 1 – 5 patients home over the past three years, with a further 16% of respondents having been involved in discussions about transfer home. In

addition, health professionals' views tended to be positive and a majority of them would consider taking a patient home to die with complex care needs, as long as they were not unstable or ventilated via an endotracheal tube.

These data add to the literature, which is currently dominated by case reports,⁹⁻¹³ by highlighting that a minority of healthcare professionals who responded to this survey reported experience with transferring a patient home to die.. The reported frequency of transferring patients home to die (between 1-5), proportional to the number of critical care deaths is low, with units seemingly only transferring a few patients home to die each year, if the practice is well embedded.⁶⁻⁸ While the number of transfers is modest this number mirrors the international literature in countries⁹⁻¹³ where cultural issues have not been instrumental in driving the development of this practice.

A substantial part of the survey focussed on investigating healthcare professionals' views towards transferring critical care patients' home to die. Doctors and nurses in our sample held largely positive views about transfer home to die from critical care, while a minority of respondents agreed with negative items stating for instance that transfer home is a waste of health service resources or that staff in critical care have more pressing clinical priorities than transferring patients home to die. These more negative views might in part contribute to the fact transfer home is relatively rare. Negative views are rarely reported in the literature, except for one opinion piece, which challenged the practice of transferring a patient home to die from critical care if a patient were unconscious.²⁵ The assertion was made that this would not benefit the patient and therefore the practice targeted at relatives.²⁵

The overwhelmingly positive views held in the literature might suggest that experience of a transfer influences views and attitudes about this practice. Indeed the subgroup

analyses carried out showed that respondents with experience were likely to report higher average scores in terms of agreement with the feasibility and necessity of transfer home to die. These findings, combined with the positive accounts in the international literature, suggest that facilitating a positive experience for clinicians may increase the likelihood of a transfer being offered to patients at the end of life. It may be that views and experience reciprocally influence each other with negative views prohibiting engagement with transfer home and positive experiences influencing views, in turn leading to more active engagement with the possibility of transfer. Future studies should investigate this assertion through for instance a simulation or an intervention guiding inexperienced clinicians through the transfer process.

Further subgroup analyses also demonstrated differences between nurses and doctors. Results were reflective of findings in the end of life literature in critical care where the differences in medical and nursing staff views have been ascribed to different professional philosophies²⁶ and informed by the key focus of the clinical role held²⁷. Nursing staff in the survey were more positive regarding statements concerning patient needs led care and medical staff, who frequently managed and were responsible for more than one critically ill patient, were more negative towards comments that had wider workforce/resource implications.

In terms of patient characteristics, critical care health care practitioners identified that patients who were unstable, ventilated via an endotracheal tube or needing cardiovascular support (e.g. inotropes) as less suitable for transfer home; respondents were divided in opinion about patients who were ventilated via a tracheostomy. Clinical instability has been described in the international literature as being a key limitation in relation to transfer home,⁹ although there are examples of where intubated and

inotropic dependent patients¹¹ are transferred home and then extubation and terminal weaning then occurs in the home environment.^{8,14} However, for instance in a study describing this service in a single institution the authors had made the a-priori decision to exclude patients who were supported on ventilation via an endotracheal tube.⁹ This type of ventilation represents a significant medical intervention, and withdrawal of this support often results in death within hours. This may lead clinicians to view such a transfer as cumbersome and perhaps even pointless as the absolute time the patient is at home and alive is very short. Conversely, if such a transfer is able to meet a patient's wishes and needs then this endeavour is worth the considerable effort. Differences between doctors and nurses were found in terms of patient characteristics, potentially highlighting the different responsibilities linked to the professions.

Study limitations

As a web-based self-report survey, this study was easy to administer and checks for face and content validity were put in place. However, self-report surveys have limitations that require acknowledgement including the possibility of inaccurate self-reporting caused by recall bias. The response rate of 23.8% is reflective of the lower response rates expected with web-based surveys,²⁸ and there is a risk of non-response bias. In addition, it is possible that health care practitioners with an interest in end of life care were more likely to complete the survey, which may have contributed to the positive responses on the statements about their views.

Conclusion

This paper has explored an end of life initiative that considers how preferred place of death can be operationalised within the critical care setting, however, this option is bounded by the clinical characteristics of the patients and the consensus view of the critical care team. Views of health professionals in the sample were generally positive, and those with more experience reported more positive views. Future studies should focus on supporting health professionals to gain experience in this practice, through simulation or intervention, to improve informed decision-making. In addition, building consensus around characteristics of patients which merit transfer and supporting guidelines might improve choice and care at end of life in critical care.

Ethical approval was gained for the study via IRAS (REC reference 11/SC/0031).

Declaration of conflicting interests

None

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Figure 1. Structure of web-based survey

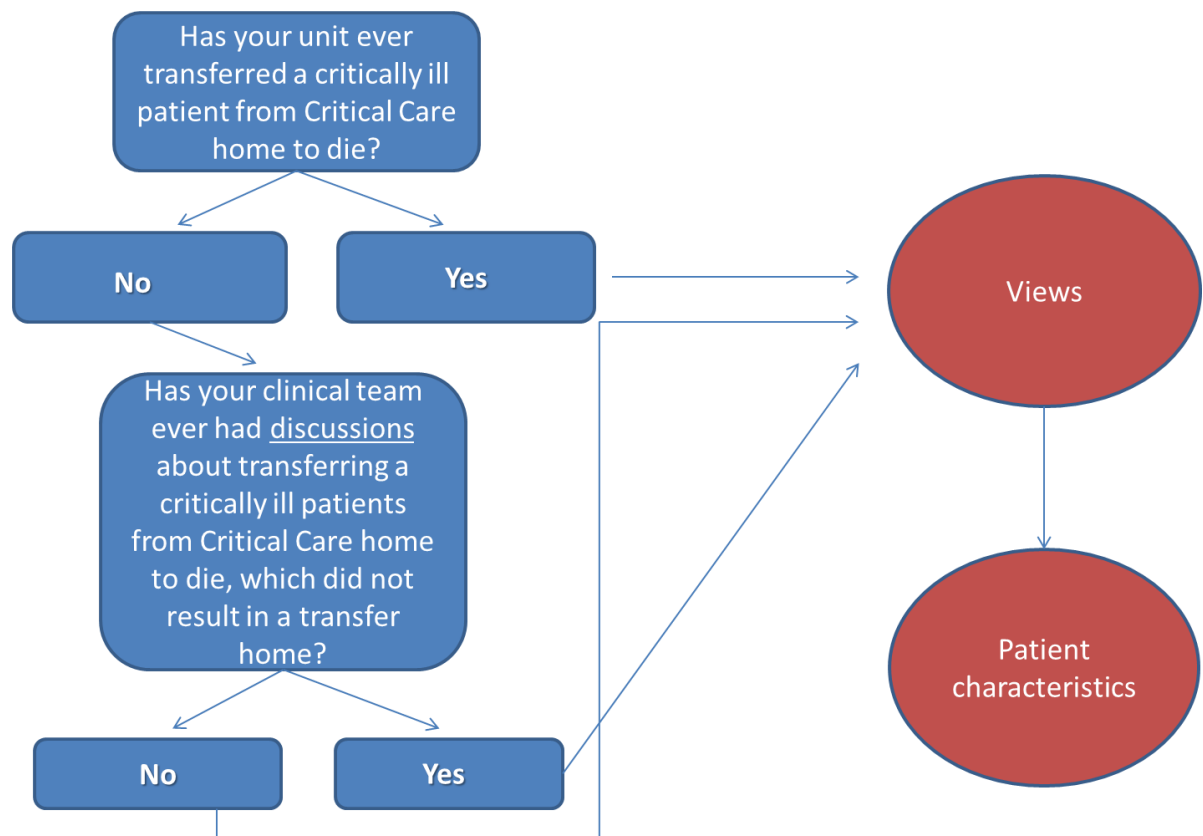


Table 1. Responses of participants to statements, in raw numbers, percentage and means (SD).

	1 Strongly disagree	2 Disagree	3 Neutral	4 agree	5 Strongly agree	Median (range) Total	Median (range) Doctor	Median (range) Nurse
Transferring critically ill patients home to die is a good idea in principle but difficult to achieve in reality	0 (0%)	11 (6.5%)	8 (4.7%)	86 (50.9%)	64 (37.9%)	4 (2-5)	4 (2-5)	4 (2-5)
Critical care is a perfectly good place to die	16 (9.4%)	54 (31.8%)	69 (40.6%)	30 (17.6%)	1 (0.6%)	3 (1-5)	3 (1-4)	3 (1-5)
I have limited experience of transferring patients home to die and wouldn't know where to start	8 (4.7%)	60 (35.5%)	42 (24.9%)	45 (26.6%)	14 (8.3%)	3 (1-5)	3 (1-5)	3 (1-5)
It is better for critically ill patients to die in Critical Care	28 (16.5%)	74 (43.5%)	62 (36.5%)	5 (2.9%)	1 (0.6%)	2 (1-5)	2 (1-4)	2 (1-4)
It would be better to transfer a patient to a hospice than to transfer them home to die	18 (10.5%)	69 (40.4%)	70 (40.9%)	11 (6.4%)	3 (1.8%)	2 (1-5)	3 (1-4)	2 (1-5)
It is satisfying to enable a patient to die at home	0	2 (1.2%)	25 (14.8%)	79 (46.7%)	63 (37.3%)	4 (2-5)	4 (2-5)	4 (3-5)*
We would be able to organise the transfer home to enable someone to die at home	5 (2.9%)	23 (13.5%)	40 (23.5%)	83 (48.8%)	19 (11.2%)	4 (1-5)	4 (1-5)	4 (1-5)
It is unethical to prolong a patient's life so they can be transferred home to die	11 (6.5%)	43 (25.4%)	54 (32.0%)	50 (29.6%)	11 (6.5%)	3 (1-5)	3 (1-5)	3 (1-5)
It would be too distressing for the patient and relatives to take them out of the familiar critical care environment	25 (14.6%)	90 (52.6%)	45 (26.3%)	9 (5.3%)	2 (1.2%)	2 (1-5)	2 (1-5)	2 (1-5)
Patients will still receive the best possible care if they are transferred home to die	2 (1.2%)	22 (13.1%)	60 (35.7%)	70 (41.7%)	14 (8.3%)	3 (1-5)	3 (1-5)	4 (1-5)*
Transferring critically ill patients home to die is important because patients should be able to die at home if that is their preferred place of death	2 (1.2%)	5 (3.0%)	23 (13.6%)	83 (49.1%)	56 (33.1%)	4 (1-5)	4 (2-5)	4 (1-5)***
It is more important to offer good end-of-life care on the unit than to transfer patients home to die	7 (4.1%)	60 (35.5%)	66 (39.1%)	29 (17.2%)	7 (4.1%)	3 (1-5)	3 (1-5)	3 (1-5)

Critical care staff have more pressing clinical priorities than organising home transfers for dying patients	33 (19.9%)	88 (53.0%)	25 (15.1%)	15 (9.0%)	5 (3.0%)	2 (1-5)	2 (1-5)	2 (1-5)**
Transferring critically ill patients home to die is a feasible option in critical care	5 (3.0%)	8 (4.8%)	46 (27.4%)	85 (50.6%)	24 (14.3%)	4 (1-5)	4 (1-5)	4 (2-5)**
Transferring patients home to die is not worth the risk of dying in the ambulance or having a really bad death at home	21 (12.3%)	83 (48.5%)	45 (26.3%)	18 (10.5%)	4 (2.3%)	2 (1-5)	2 (1-5)	2 (1-5)
Dying in critical care is better than home for patients because of the higher nurse patient ratios	27 (15.8%)	90 (52.6%)	41 (24.0%)	10 (5.8%)	3 (1.8%)	2 (1-5)	2 (1-4)	2 (1-5)
Taking critical care patients home to die is a waste of health care resources	55 (32.4%)	88 (51.8%)	19 (11.2%)	3 (1.8%)	5 (2.9%)	2 (1-5)	2 (1-5)	2 (1-5)**

* P<0.05, ** p<0.01, ***p<0.001

Table 2. Responses to question about characteristics that respondents would consider (or not consider) transferring, expressed as raw scores and percentages

	Doctor	Nurse	Total
is unconscious	53.7%	69.4%*	101 (61.6%)
is conscious	100%	100%	166 (100%)
is unstable	29.9%	45.3%	63 (38.2%)
is stable	100%	97.6%	163 (98.8%)
who is ventilated via an endotracheal tube	34.3%	27.9%	52 (31.5%)
who is ventilated via tracheostomy	64.7%	51.2%	96 (57.8%)
who is receiving non-invasive ventilation	66.7%	80.2%	126 (75.4%)
is self-ventilating breathing oxygen	97.1%	93.0%	159 (95.2%)
who is self-ventilating breathing air	100%	100%	167 (100%)
needs cardiovascular support e.g. inotropes	45.6%	26.7%*	57 (34.3%)
has intense nursing needs e.g. frequent turning and washing	61.2%	88.4%***	128 (77.6%)
has high level emotional needs	82.6%	90.6%	146 (88.0%)
has relatives with high level emotional needs	67.6%	86.0%**	131 (78.9%)
needs regular medication for symptom management (e.g. pain, nausea)	91.3%	89.4%	150 (90.4%)
lives outside local catchment area	76.8%	88.2%	135 (81.3%)

* P<0.05, ** p<0.01, ***p<0.001